

PAPER PARTICIPANT INFORMATION STATEMENT

Bupa Health Insurance Policy Holders
Health Insight Pilot Study
Professor Emily Banks

1. What is the research study about?

You are invited to take part in this research study. The Health Insight Pilot Study focuses on “person-centred” outcomes in health. These are outcomes that have been shown to matter most to people in their day to day lives, especially for those living with illness. These include physical disability, quality of life, mental health and wellbeing, connecting with friends and family and participating in work and community activities. The researchers want to understand more about these outcomes and how to improve them. The researchers want to understand more about these outcomes and how to improve them.

This research is being done as a pilot, or trial, study to learn more about person-centred outcomes in people with private health insurance, whether a larger study of this type is possible and how best to conduct such a study. The information gathered in the Health Insight Pilot Study will be used to decide whether a larger study, inviting many more people with private health insurance, should be undertaken in coming years

You have been invited because you are a current Bupa health insurance policy holder. You have been sent this invitation by Bupa with contact details you have given them previously.

2. Who is conducting this research?

The study is being carried out by the following researchers:

- Professor Emily Banks, Scientific Director, 45 and Up Study, Sax Institute
- Associate Professor Bette Liu, School of Public Health and Community Medicine, UNSW
- Dr Martin McNamara, Head, Research Assets, Sax Institute
- Mr Mark Bartlett, Director Data and Analysis, Sax Institute.

Research Funder: This research is being funded by The Bupa Health Foundation. The Bupa Health Foundation has provided advice to the Sax Institute on research themes relevant to private health insurance in Australia, but the design of the research is entirely the responsibility of the Sax Institute. The Bupa Health Foundation will not receive or have access to the individual responses you provide as part of this study and will only receive reports that summarise the findings, based on aggregated data.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who:

- Are current Bupa Health Insurance Policy Holders
- Are aged 18 years or over
- Live in New South Wales or South Australia.

If any of these do not apply to you, please ignore this invitation. We apologise for having troubled you.

4. Do I have to take part in this research study?

Participation in any research study is voluntary. If you do not want to take part, you do not have to.

If you decide you want to take part in the research study, you will be asked to:

- Read the information in this sheet carefully (asking questions if necessary);
- Sign the consent forms if you decide to participate in the study;
- Take a copy of this form with you to keep;
- Complete the paper questionnaire;
- Return the signed consent forms and completed questionnaire in the enclosed reply-paid envelope.

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5. What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, we ask you to read this information sheet, complete two consent forms, complete a single paper questionnaire and return completed consent forms and questionnaire in the enclosed reply-paid envelope.

- The first consent form at the end of this document seeks your consent to opt in to the pilot study.
- The second consent form seeks your consent to opt in to having contact information you provide as part of the pilot study kept securely, so we can let you know about the outcomes of the Pilot Study and invite you to join a possible future full-scale study, if it goes ahead.
- The questionnaire will ask you questions about your health including: physical functioning, mental health, quality of life, pain, social support, and economic engagement. It should take approximately 25-30 minutes to complete. There is no follow up to this questionnaire as part of this study.

We don't expect the questionnaire to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance.

If this Study Pilot is successful, the people who have taken part in the pilot study will be invited to participate in a larger study. Participation in the larger study will be voluntary and you could refuse to participate if you choose.

The information you provide will not be shared in an identifiable format and will not affect your private health insurance or health care in any way.

6. What are the possible benefits to participation?

We will use the information from you to understand more about person-centred outcomes in people who hold private health insurance. We will also use information from this research study to understand whether it is possible to do a large study among people with private health insurance to improve health and health services in Australia.

7. What will happen to information about me?

Submission of the online questionnaire is an indication of your consent. By clicking the 'I agree to participate' button you are providing your permission for the research team to collect and use information about you for the research study. Your data will be kept for a period of 7 years after the project's completion (mid 2019). We will store information about you that you provide in response to the questionnaire in a non-identifiable format at the Sax Institute. Your information will only be used for approved health and health services research. Information collected for this research project may be made available to other approved research projects in non-identifiable form only.

If you choose to provide consent to have your contact information stored in the Health Insight Study Databank, the Sax Institute would store your identifying personal information (contact information) in a separate database that is not accessible to the staff who have access to your non-identifiable questionnaire responses. Please see the separate Participant Information Statement and Consent (PISCF) Data Banking Form for the Health Insight Pilot Study for further details.

8. How and when will I find out what the results of the research study are?

The research team intend to publish and/ report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you. If you would like to receive a copy of the results you can let the research team know by adding your email or postal address within the consent form. We will only use these details to send you the results of the research.

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9. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively, you can ring the research team on 1300 16 34 26 and tell them you no longer want to participate. If you decide to leave the research study, the researchers will destroy any information that has already been collected and no additional information will be collected from you. Your decision not to participate or to withdraw from the study, will not affect your relationship with the Sax Institute, Bupa or the Bupa Health Foundation.

The information you provide is personal information for the purposes of the *Privacy and Personal Information Protection Act 1998* (NSW). You have the right of access to personal information held about you by the Sax Institute, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act.

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact

Name	Alison Cowle
Position	Cohort Manager, Sax Institute
Telephone	1300 16 34 26
Email	healthinsightstudy@saxinstitute.org.au

What if I experience distress?

If you experience distress while completing the questionnaire, please contact the research team for advice, or use the following numbers to contact a counselling service:

Phone Counselling Services

Organisation	Lifeline	Beyond Blue Infoline
Telephone	13 11 14	1300 22 46 36

11. What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC180524

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Consent Form – Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet or it has been provided to me in a language that I understand;
- I understand that if necessary I can ask questions and the research team will respond to my questions;
- I understand that I can download a copy of this consent form from:
www.saxinstitute.org.au/our-work/health-insight-pilot-study/;
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Full name: _____

Postal address: _____

Email Address: _____

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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** affect my relationship with the Sax Institute, Bupa or the Bupa Health Foundation. In withdrawing my consent I would like any information which I have provided for the purpose of this research study withdrawn.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Professor Emily Banks
Email:	healthinsightstudy@saxinstitute.org.au
Phone:	1300 16 34 26
Postal Address:	The Health Insight Pilot Study, GPO Box 5289, Sydney NSW 2001